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CASE STUDY

'Ageing Playfully': a story of forgetting and remembering

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ABSTRACT

An increasing interest in exploring how digital innovation could support dementia care has been a leading research responding to e-health movements, from caregiving and medical perspectives. Little research has included perspectives of people with dementia; even fewer are concerned with the emotional side of the research experience per se. The aim of this case study is to open a space for a discussion of the impact that this process has on design researchers engaging in the area of dementia. Grounded in these two overlapping creative spaces, a methodology emerged that focused on adding design value to outcomes and to all stakeholders involved along the process. The Ageing Playfully project explored, through a series of playful workshops, the opportunities available for people with dementia to catalyse imagination and social interaction through co-design. Participating in Ageing Playfully were 12 co-designers with dementia, 2 healthcarers and 4 researchers from Lancaster University working in the areas of design, computer science and health studies. This paper recounts the experience of the design researchers as part of the team and constructs a narrative in which emerging methods together with personal experience are protagonists; a story that offers memories within the forgetful corners of the investigation.

Introduction

Ageing Playfully was a cross-discipline, cross-sector collaboration project funded by the UK Arts and Humanities Research Council (AHRC), through the Creative Exchange programme, one of its four Knowledge Exchange Hubs for the Creative Economies. The main aim of the Creative Exchange was to catalyse collaborations of academics and private and public sector. Ageing Playfully brought a team of researchers and healthcare practitioners from Age UK Lancashire to work with a community of people in the early stages of dementia and their

caregivers. The idea of the project was to use co-design processes to explore the potential of digital–physical interventions to boost wellbeing for people with dementia. Through co-design methods, the project endeavoured to contest the 'ill', 'un-able' or 'patient' identities that are continuously constructed and reinforced in medical context (Mol and Law 2004, 02). Ageing Playfully envisioned that creative and participatory activities empower participants and offer space to recover 'active' identities and to reclaim agency by becoming designers themselves (Luján Escalante, Salinas, and Moffat 2017).

Method Story (Hendriks, Slegers, and Duysburgh 2015) is a novel approach for sharing experiences and questions about co-design methods and techniques for involving people with memory problems. Method Story has been employed in this paper, on the one hand, to make sense of the experience by remembering it and articulating it in a story format, and on the other hand, to go beyond the publication of the positive results of design research. In this sense, it is not the aim of this paper, for example, to contribute to the understanding of how dementia might impact upon the person, not even to understand how digital–physical technologies may be used to boost wellbeing of people with dementia. Using the Method Story, this paper opens a critical space for making sense, and questioning, the role of the design researcher when working together with people with early signs of dementia and their caregivers.

The contribution to the design perspective is to share explicitly the making of the methodological approach, including the considerations, decisions and adaptations that influenced the empathic design of our research. As researchers and authors of this paper, we take the opportunity offered here to reflect on how the research transformed our own story as researchers, and the unexpected outcomes that resulted from the quest of co-designing with people with dementia and their caregivers.

After presenting the related work, the paper focuses on discussing and sharing the research team's experience in the Ageing Playfully project using the Method Story. To test the Method Story, the structure of the discussion follows section by section the one proposed by Hendricks, Slegers, and Duysburgh (2015). This is then followed by concluding remarks.

Related work

Designers are increasingly participating in and leading dementia-related research projects. This has emanated from an urgent societal need for improving the quality of life of people with dementia and their caregivers, following the steep increase of dementia in the UK (Prince et al. 2014) and worldwide (Prince 2015), as well as its rising cost for healthcare services (Prince et al. 2014).

Following a growing research literature reporting on the social needs in dementia (Vogt et al. 2012; Kitwood and Bredin 1992), much of this work has focused on designing interventions aimed at people at the early stages of

dementia and their caregivers. This ranges from facilitating reminiscing and enhancing personhood (Wallace et al. 2013; Siriaraya and Ang 2014; Kuwahara et al. 2006); to addressing the safety and autonomy of people with dementia (Mountain 2006; Lindsay et al. 2012; Robinson et al. 2009) and supporting activities of daily living (e.g. cooking, improving sleep) (Ikeda et al. 2011; Ehleringer and Kim 2013; Hoey et al. 2011).

Within this context participatory design has been widely employed as a research method with the aim of engaging people with dementia and their caregivers and designing *with* rather than *for* service users (Hanson et al. 2007; Robinson et al. 2009; Mayer and Zach 2013; Lindsay et al. 2012; Treadaway, Kenning, and Coleman 2015). However, the exact notion and nature of participatory design within the context of working with people with dementia and limited capacity raises several ethical challenges and concerns (Berghmans and Ter Meulen 1995; Baldwin 2005; Dewing 2007).

There has much written on ethical issues and the transformative implications of conducting research in the space of dementia from various disciplinary points of view (e.g. Woods and Pratt 2005; Strech et al. 2013) and caregivers (Hughes et al. 2002). However, little has been written from the point of view of the increasing number of design researchers engaging in the area of dementia. Participatory processes do not just empower and offer agency to participants but also transform the design researcher's practice, ideas and perspectives, and these important implications are rarely addressed among scholars. Findings and outcomes of design research in publications and conferences are usually limited to either participants or to design products, services and processes. This omission presents the design researcher as discrete, neutral or permeable to the transformative process of participatory design. This paper uses the Method Story to unveil the transformative implication of participatory design process to the researcher 's practice.

Discussion

Positioning Dementia

Twelve participants with dementia provided consent to take part in Ageing Playfully and were supported at the workshop sessions by two healthcarers. Although one member of the research team had experience in the context of dementia, specifically using art therapy, this was the first time that everyone had designed together with people with dementia. This was a significant challenge for all members of the research team. We quickly learned that the word 'dementia' carried negative connotations and stigma, not just for researchers, like us, but also for the people with dementia, their caregivers, family and even healthcare professionals. The first thing we learned was to focus on people as people rather than on dementia and to concentrate on wellbeing instead of ill-being.

Training was provided offering insight into dementia by Age UK professionals from Lancaster. This proved invaluable for the research team and offered more confidence on how to approach the group of people it was going to work with.

Age UK Lancashire had been working for approximately a year with a 'circle of support' that the project was going to join and engage as a focus group. The contrasting languages of dementia as chronic illness and the narratives from the 'circle of support' as a social group that engage in theatre and dancing was starting to show the research team the liminal spaces in which the workshop was going to emerge; in between medical and creative, with the participation of subjects/objects.

Building relationships and understanding of group members were essential. This was facilitated through attending the 'circle of support' sessions for a period of approximately two months prior to initiating the workshops. This period of all the participants getting to know each other was essential. We had the opportunity to share social contexts and we participated with the group's activities, becoming familiar with the ways different participants expressed their experience of dementia and the way carers show attention and care for them.

The 'circle of support' met every week at an elderly care home with a dementia care and rehabilitation unit, in the suburbs of Lancaster. The team was certainly nervous; preconceptions embodied in images of a madhouse and asylums were obscuring the golden autumn day and preventing some of the researchers from advancing each step. The home very quickly dissolved researchers' fears and erroneous preconceptions. In the first visit, the research team sat at the back of the room and observed (see Figure 1). We had little participation in the session. The session was led by two healthcare practitioners from Age UK. One, who we will call P, impressed us with his enthusiasm and how all participants seemed to like this. The research team doubted it ever would have such energy to facilitate a session like him. The other one, who we will call S, was loving and caring, calm and patient. We noticed she talked to each individual with love and tactile communication. Again, a question arose in the back of the research team's mind; where or how would we find and offer a similar level of caring attention in the participatory design sessions?

We continued to attend the older people's home on a weekly basis, gradually finding ourselves more at ease and even participating in the sessions. By the end of this two months, we discovered that we were actually looking forward to our weekly afternoons with the support circle and were happy to be sharing time and songs with them.

This period helped to dispel our preconceived ideas about who people with dementia are. Indeed, it was realized that it is not always obvious that someone has dementia, particularly when they are in the early stages of the disease. Based on the notes of this preliminary experience, we started to meet as part of the research team, and we began to give shape to the methodology, aware that we must include the participants in the design process.

Figure 1. The research team's first day with Age UK Lancashire Circle of Support at the older people's home in Lancaster.

Aiming for equivalence

The broad idea was that together as a team of researchers we would facilitate a series of playful workshops. Co-design processes meant that researchers had to allow an equality of control over the process between the team as facilitators and participants as co-designers. What were these workshops about? What were the main themes? What would we co-design? What were the expected outcomes? We did not know at that time. The idea was to answer this essential research question during the process with the participants. In this sense the co-design process does not just encourage a degree of equity in research hierarchies, whether participant and researcher, but also encourages flexibility in the methodology. The only thing clear to the research team at that point was that it had to include somehow its very own version of P's enthusiasm and S' caring attention in order for these workshops to be successful.

The research team was interdisciplinary. Amanda is a health researcher, based in the faculty of Health and Medicine; her main contribution to the project was her vast experience using art therapy in research process. Emmanuel brought expertise in co-design methods to explore the intersections of digital technologies and wellbeing and Malé, who was doing her PhD degree in Digital Cultures, brought experience in design ethnography but had never worked in a health

context. Together, inspired by P and S, and cleansed of the bad connotations the word dementia carries, we initiated the workshops.

Balancing of viewpoints

Part of the task of designing the methodology was dealing with the expectations of all the partners. This involved negotiating tensions between the delicacy of memory processes and the gleam of technological innovation; the fragility of the process of collaborative ideation with participants who, most of the time, had forgotten what was discussed in the last engagement against the sharpness of institutional interests in impact outcomes. For instance: 'what are you designing?' Such occurrences illuminated the particular and sensitive place that dementia has in the public imagination and specifically in a healthcare context.

The first phase of project focused on four workshops; each of these would inform the next one. By the end of the first workshop, we expected to learn the main themes of interest from participants which we would explore in the remaining workshops (see Figure 2). We aimed to end with one or more prototypes or ideas that would be developed in the design lab in the second phase of the project.

Dealing with ethical challenges

Following ethics review and approval by the Lancaster University Research Ethics Committee (UREC) and additional permission obtained from the Age UK Lancashire (Lancaster), the research team introduced the project in one of the weekly sessions of the 'circle of support', involving carers and support workers in the discussion. Information packs including consent forms were distributed and those wanting to take part were invited to join the first Ageing Playfully workshop.

Written consent was obtained at the start of the first workshop with the assistance, where needed, of carers and support workers. We knew through participants' family and relatives and from Age UK caregivers that people from 'circle of support' were keen to participate. We were confident that all the research team were committed to facilitate the best experiences for the participants. However, that did not stop us asking ourselves in what measure those permissions would be ethically valid when, during the course of the research project, some of the participants may not remember what they had signed up for. We could not help but feel that we had some co-designers that were there with a potentially declining agency to own and respond to the design process. Working with people with dementia raises ethical questions during the whole process and made the design researchers critically evaluate their role, responsibility and rights as researchers, as well as their rights to research.

During the workshops, participants as co-designers expressed enjoyment and enthusiasm when given this opportunity to engage playfully with each other in

Figure 2. Workshop One: 'Our favourite things': show how themes began to emerge.

imagining and building models (see Figure 3). Their carers and support workers noted how the workshop activities seemed to encourage interaction, with even the reticent, less confident members of the group joining in with the model building. The series of workshop finalized with impressive outcomes: a co-design tool kit and a musical board.

Figure 3. Workshop Two: 'Our very own garden': co-designers modelling their ideal garden and garden activities and features.

The second phase of the project in the design lab would not involve the co-designers. However, during the eight weeks of this first co-design phase, participants appeared to create social connections and some emotional links. There was a sense of friendship between some members of the group and some valued moments when they shared personal stories that certainly enriched the project. As a team we were very aware of how the potential for this level of friendly, social interaction was abruptly disrupted by the termination of the project.

Once again, we asked ourselves if we have the right to offer participants a chance to build such a potentially important and most needed space and then, at the end of the project, to suddenly cut them out from it. The project benefited us as researchers from a series of data collection, ideas and prototypes. We have no doubt that all researchers were always thoughtful about offering a meaningful experience in return. The project was always scoped for a limited period of time and the awareness of termination was present. But it felt that the experience was too meaningful and the termination meant a sense of loss for the participants who were already losing a lot. Perhaps this is the norm for this type of pilot project, especially in a charitable context. However for several of us, as this was our first project in this area, it was harder than anticipated.

The project scope included a session of feedback. We were supposed to show all the models and prototypes, show the videos we made together, and provide

closure to the experience. Lamentably, this last session could not happen, as in the process a change in funding sadly the 'circle of support' group was no longer able to take place.

Care matters: after ageing playfully

Beyond the impact and outcomes of the project, beyond the methodology and methods, and beyond the project report, Ageing Playfully opened a door for the team in new research interests. By the last session of the workshops, we had learned the names and personalities of all the participants, we sustained weekly correspondence with them during and after the sessions, and got to know them and their life stories a little bit. For the research team, the end of the project was painful. On the other hand, we developed our own – less refined and perhaps less efficient – version of P's enthusiasm and S's care. Fundamentally, we found a research interest in continuing to work with older adults and people with dementia.

Ageing Playfully opened a door for us to develop research interests in care and how care matters in the context of involving digital technologies to mediate experience of chronic illness. Currently, digital technologies are interfaces for body data collected and interpreted from the medical perspective and for medical use. The questions we asked ourselves during the project directed new research into a theoretical and methodological search that integrates the emotional textures and qualities of care into the binary objectivity of the digital.

All these connections, exploratory conversations, theoretical research and work after Ageing Playfully are reshaping not just our research profiles, but have also transformed our personal lives and the vision of our future practice. We ask ourselves again is this not also an outcome of Ageing Playfully project? We have a sense that we owe our current research direction to Ageing Playfully's 'afterlife,' but there is rarely space in a research paper or report to express the implications one small pilot project may have in the life of the researchers and the experience of research. We took the opportunity of this method story not just to recount how methods emerged, essentially out of enthusiasm and care, but to tell a much bigger tale of remembering why we get to care and how.

Conclusions

The project outcomes included a design brief for a music-related intervention for social interaction and a set of practical recommendations for researchers, informal and professional carers in running workshops using playful activities that mediate active social interaction and stimulate engagement and contribution to knowledge. These outcomes were shared and published within academic and non-academic contexts. However, the experience of developing co-design research methods, alongside the practice of co-designing and what the research means to the researchers never found a space for sharing or getting feedback.

The story of the method (Hendriks, Slegers, and Duysburgh 2015) seems not just to be a useful medium for this, but also, a healthy strategy for researchers that may find themselves engaged in the research from rather emotional processes. This is a way to deal with the anti-climax of the process, as well to share learning and experiences that do not usually have a place in outcome-based reports. This storied experience centred on the methods has enormous potential for experimenting with format. Method Story is a tool that can enrich future practices and offer space to share emerging knowledge that would enrich both practices and practitioners.

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Disclosure statement

Funding

Notes on contributors

Maria A. Luján Escalante is a Creative Exchange researcher in the area of Digital Public Space, exploring materiality and in-materiality of physical–digital experiences in making. Maria is especially interested in memory processes and time experience that she is approaching by experimenting with diffractive methodologies.

Emmanuel Tsekleves is a senior lecturer in design interactions at Imagination@Lancaster in Lancaster University. Emmanuel leads research at the intersection of design, health, well-being and technology at the Imagination@Lancaster research lab. He conducts research in the design of technology-inspired health interventions and services, which are created by end users and are aimed at improving the quality of life and wellbeing of people into old age, including people with chronic health problems.

Amanda Bingley is a lecturer in health research in the Division of Health Research, Faculty of Health and Medicine of Lancaster University. Amanda is involved in work with the Centre for Ageing Research and has an interest in research with older (and younger people) with a focus on health and place. When facilitating research with people of all ages, she works with a range of qualitative approaches including narrative, ethnographic, creative arts and participatory research methods.

Adrian Gradinar is a Creative Exchange PhD student conducting research in the Internet of Things and how digital information can be integrated with familiar objects. Adrian is also

interested in game design theories and how digital games could be interconnected with the physicality of the surrounding world.

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